Psychosocial Crisis in Diabetic Renal Failure

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Twenty-nine diabetic renal failure patients suffered a psychosocial crisis at the time when chronic dialysis or renal transplantation was required. These patients could be classified into groups as to the impact of the crisis in terms of participation in life-support therapy. Group 1 consisted of potentially lethal mechanisms (9 patients): discontinued dialysis (5); refused to start dialysis (3); overt act to cause personal harm (1). Group 2 contained probably nonlethal mechanisms (11 patients): threatened to discontinue dialysis or to never start dialysis if not given a chance for a transplant (5); threatened to discontinue dialysis or to never start dialysis (5); threatened to cause personal harm (1). Group 3 consisted of a combination of mechanisms (9 patients): with drug abuse (4); without drug abuse (5). Important similarities between the groups were easier to document than were subtle differences in the kinds of options in family and employment relationships; in the degree of objective and subjective handicap due to impaired vision; in the level of expectation and/or disappointment following renal transplantation; and in the capacity to cope with changing personal relationships produced by the complications of diabetes.

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Prolonging the life of diabetic patients with renal failure has become possible within the past 10 yr as techniques for dialysis and transplantation have become widespread. Several studies have dealt with the adjustment process necessary to achieve psychosocial stability as dialysis is initiated and transplantation is subsequently performed.[1,2] Rehabilitation of the multiply handicapped individual hinges strongly on family-type support systems, but self-motivation must surely be operative for success. Diabetic patients usually have many years to develop attitudes toward their future quality of life with an increased possibility of blindness, amputation, ischemic heart disease, and renal failure. These feelings plus those which rapidly emerge from family, friends, counselors, other patients, and members of the health care profession present infinite possibilities for frustration of the patient as prime decision maker. At times a crisis occurs for the individual who doubts that the demands of life on chronic dialysis or following renal transplantation are compatible with the rewards.

In an attempt to improve care of diabetic patients with renal failure who are approaching a psychosocial crisis, we reviewed our experience and identified first a number of relatively compliant patients who were notable in their ultimate decision to either forego dialysis entirely or to discontinue this therapy. In the process, we uncovered a second general category of individuals who, despite threats to avoid dialysis, were actually rather consistently cooperative, suggesting that they had resolved a difficult psychosocial situation. Finally, we reviewed a series of patients whose diet-insulin management had never been worked smoothly into their adult lives so that any further demands of renal failure therapy might result in life-threatening noncompliance.

PATIENTS AND METHODS

Charts were reviewed for background information on patients with diabetic renal failure whose adjustment to the prospect of life on dialysis could be characterized according to the mechanisms outlined in Tables 1 and 2. The study was retrospective and covered the years 1973–79. No single coauthor was familiar with each patient, but several had worked closely with the majority of these individuals. The 29 study patients represented about 10% of the total number of patients with diabetic renal failure seen at the New England Deaconess Hospital and the Joslin Clinic during the study interval. This suggests that many diabetic renal failure patients

TABLE 1
Background data

	Patient no.	Sex	Age*	Marital status	Children	Years of Diabetes	Years of Dialysis	Type of transplant Cadaveric	Type of transplant Live-related
1. Potentially lethal mechanisms									
A. Discontinued dialysis	1	M	28(−)	Sep	1	24	<1	1	0
	2	F	23(−)	S	0	18	2	0	1
	3	F	22(−)	M	0	15	2	0	1
	4	F	23(−)	S	0	16	2	1	0
	5	M	37(−)	M	2	23	2	0	0
B. Refused to start dialysis	6	M	30(−)	S	0	20	0	0	0
	7	F	27(−)	S	0	20	0	0	0
	8	F	66(−)	M	1	28	0	0	0
C. Overt act to cause personal harm	9	M	42(−)	S	0	1	<1	0	1
		4 M	33 yr	5 single	3 with	19	1	2 with	3 with
		5 F	0 alive	3 married	6 none			7 none	6 none
			9 dead	1 separated					
2. Probably nonlethal mechanisms									
D. Threatened to discontinue dialysis or to never start dialysis if not given a chance for a transplant	10	F	48(+)	Sep	1	28	0	1	0
	11	F	52(+)	M	2	20	0	0	1
	12	M	32(+)	D	0	18	3	1	0
	13	F	55(+)	M	0	18	1	0	0
	14	F	34(+)	S	0	19	0	1	0
E. Threatened to threaten to discontinue dialysis or to never start dialysis	15	M	27(+)	M	1	17	1	1	0
	16	M	29(+)	M × 2	0	16	<1	0	0
	17	M	37(+)	M × 2	3	32	4	0	0
	18	F	39(+)	Sep	0	25	<1	0	0
	19	F	55(+)	D	0	22	0	0	0
F. Threatened to cause personal harm	20	M	28(+)	M × 2	2	14	1	0	0
		5 M	40 yr	5 married	5 with	21	1	4 with	1 with
		6 F	11 alive	2 separated	6 none			7 none	10 none
			0 dead	2 divorced					
3. Combination of mechanisms									
G. With drug abuse	21	F	33(+)	D	0	16	<1	0	1
	22	M	41(−)	D × 2	2	30	<1	1	0
	23	M	32(+)	D	1	26	1	0	1
	24	M	25(−)	S	0	22	<1	0	0
H. Without drug abuse	25	F	34(−)	S	0	23	<1	0	0
	26	M	39(−)	M	2	21	2	0	1
	27	M	38(−)	D × 2	2	23	1	0	0
	28	M	27(+)	S	0	22	<1	0	0
	29	F	58(+)	W	2	35	3	0	0
		6 M	36 yr	4 divorced	5 with	24	1	1 with	3 with
		3 F	4 alive	3 single	4 none			8 none	6 none
			5 dead	1 married					
				1 widow					

* (+) = alive; (−) = dead.

with difficulty adjusting to the prospect of life on dialysis were not included because their adjustment process evolved sufficiently enough to avoid psychosocial crisis. No attempt has been made to apply methods for objective testing of the psychological processes of these individuals or for rigorous analysis of the epidemiology of psychosocial crisis in diabetic renal failure.

The decision to discontinue dialysis or the refusal to ini-

TABLE 2
Psychosocial crisis associated with patient losses

	Patient no.	Usual family relationships	Gainful employment	Starting dialysis	Visual loss	Locomotor dysfunction	Dialysis access	Transplant function
1. Potentially lethal mechanisms								
A. Discontinued dialysis	1	yes	no	yes	3+	2+	no	yes
	2	yes	no	yes	4+	2+	yes	yes
	3	yes	yes	yes	3+	2+	yes	yes
	4	no	no	no	4+	1+	no	yes
	5	no	yes	yes	4+	1+	yes	no
B. Refused to start dialysis								
	6	no	no	no	4+	3+	no	no
	7	no	yes	no	4+	2+	no	no
	8	no	yes	yes	4+	1+	no	no
C. Overt act to cause personal harm	9	yes	yes	no	0+	0+	no	no
		4 yes	5 yes	5 yes	8 yes	8 yes	3 yes	4 yes
		5 no	4 no	4 no	1 no	1 no	6 no	5 no
2. Probably nonlethal mechanisms								
D. Threatened to discontinue dialysis or to never start dialysis if not given a chance for a transplant	10	yes	yes	yes	4+	1+	no	no
	11	no	no	yes	1+	0+	no	no
	12	no	no	yes	4+	0+	no	no
	13	no	no	yes	2+	1+	no	no
	14	no	yes	no	2+	0+	no	no
E. Threatened to threaten to discontinue dialysis or to never start dialysis	15	yes	yes	yes	2+	1+	no	yes
	16	yes	yes	yes	2+	1+	no	no
	17	yes	yes	no	4+	3+	no	no
	18	yes	yes	yes	1+	0+	no	no
	19	yes	yes	yes	4+	3+	no	no
F. Threatened to cause personal harm	20	yes	no	yes	2+	1+	no	no
		7 yes	7 yes	9 yes	11 yes	7 yes	0 yes	1 yes
		4 no	4 no	2 no	0 no	4 no	11 no	10 no
3. Combination of mechanisms								
G. With drug abuse	21	yes	yes	yes	1+	4+	no	no
	22	yes	yes	no	2+	1+	no	no
	23	no	no	yes	3+	4+	no	no
	24	yes	yes	yes	3+	1+	no	no
H. Without drug abuse	25	yes	yes	yes	3+	0+	no	no
	26	no	yes	yes	2+	0+	no	no
	27	yes	yes	yes	4+	1+	no	no
	28	no	yes	no	3+	1+	no	no
	29	no	no	yes	4+	3+	yes	no
		5 yes	7 yes	7 yes	9 yes	7 yes	1 yes	0 yes
		4 no	2 no	2 no	0 no	2 no	8 no	9 no

tiate this treatment was reviewed in depth with the patient, family, and any other counselors, friends, clergy persons, or primary physicians who might wish to help the patient. Psychiatric review of the patient's mental competency has become a routine requirement in all proceedings of hospital dialysis-transplantation committees.

An overt suicidal act occurred only once in this study. This young man became insulin-dependent and suffered a typically diabetic complication (vertebral body osteomyelitis) only after glucocorticoid therapy for a successful live-related transplant. He was most probably disturbed over the prospects of long-term diabetic complications, but, in fact, was physically well at the point of emotional crisis. The crisis, precipitated by separation from his fiancee, led directly to fatal drug overdose. Another young man merely verbalized direct threats to cause personal harm at a critical point when pericarditis with pericardial tamponade had occurred.

The category listed as combination of mechanisms in-

cludes patients with a wide spectrum of medical noncompliance ranging from mild dietary indiscretion to gross abuse of every aspect of self-care including drug abuse. At some point one member of the health care team might describe a diabetic patient on dialysis exhibiting oversights in self-care as suicidal while another member of the team might interpret mistakes in dietary or fluid intake, oversights in insulin or antihypertensive drug intake, the mishandling of sterile dressings, or manipulation of the dialysis schedule as a simple attempt to gain attention not previously available at home. Psychopathologic problems appeared to be widespread within the families of patients in this category, extending to multiple generations. We had the greatest difficulty understanding group 3 patients. These individuals employed many mechanisms, including the various threats listed for group 2 patients as well as a degree of noncompliance potentially as lethal as those mechanisms listed for group 1 patients.

On the other hand, every co-author understood implicitly that mere verbalization of intention to discontinue dialysis did not invariably initiate a process leading to suicide. Usually the motive could be detected: for one patient this was a signal to a sibling who had not volunteered to donate a kidney; for another it was a means of startling her father into providing more emotional support. If the patient used this indirect sort of threat at home, but not at the hospital, it was usually an instrument for leverage over a spouse perceived as abandoning the family.

Quantification of losses in Table 2 was not possible. In a gross sense visual handicap could be listed as 4+ if both eyes were completely blind, 3+ if the patient's vision allowed for no more than "getting around" in familiar surroundings, 2+ if driving a car was possible while reading a book was not, and 1+ if the handicap could largely be corrected with lenses. Locomotor limitations were graded as follows: 4+, bedridden; 3+, only able to transfer from bed to chair; 2+, walk with assistance; 1+, limited range, but essentially independent.

RESULTS

Within the overall study group of 29 patients exhibiting psychosocial crises associated with diabetic renal failure, there were three nearly equal subgroups. Nine individuals employed potentially lethal mechanisms (group 1), 11 employed probably nonlethal mechanisms (group 2), and 9 demonstrated a combination of mechanisms (group 3). All the 9 patients in group 1 have died. Causes of death were uncontrolled uremia in 8 patients who rejected dialytic therapy and a drug overdose in one instance of an overt suicidal act in a relatively physically healthy patient. None of the individuals in group 2 have died. Five of the 9 patients in group 3 are deceased.

Several important differences between groups 1, 2, and 3 are summarized in Table 1. There was no sex predominance in groups 1 and 2, whereas males were in the majority in group 3. Group 1 patients were youngest despite inclusion of one person whose age was twice the average. Group 1 and 2 patients were usually living alone or with their parents either because they had never married or because their marriages had failed. As a result most group 1 patients had no children. On the other hand, despite the fact that all group 2 patients had been married, the majority still had no children. The groups were similar with regard to duration of diabetes and dialysis as well as relative numbers of renal allograft transplant recipients.

Apparently, the failure of a renal transplant was a very critical setback, if not the final blow for four of the five diabetic patients who eventually decided to discontinue dialysis. The interval from failure of transplant function to discontinuation of dialysis was less than 3 mo in two instances, but greater than 1 yr in the other two individuals who never completely recovered from the disappointment of rejecting a family kidney.

This last point is also addressed in Table 2, which attempts to focus on losses suffered by the patients. In addition to the acute deprivation associated with failure of the transplant allograft, patients who eventually discontinued dialysis also had more threats to survival from loss of dialysis access sites. Two of three individuals with temporary clotting of an arteriovenous fistula required intermittent peritoneal dialysis, which was an equally unacceptable alternative at the point of final decision to discontinue dialytic therapy.

Although group 1 patients did not differ statistically in their perceived "losses" of family relationships or of gainful employment when compared with group 2 or 3 patients, their relationships were already so dependent that there was very little opportunity for a choice among alternatives.

There were some important group differences with regard to loss of vision. Eight of the 9 patients in group 1 as well as 6 of the 9 group 3 patients were in an advanced state of visual deterioration. By comparison, 7 of the 11 patients in group 2 had significantly lesser levels of visual impairment, allowing them a much greater measure of independence. The three groups were roughly comparable with regard to loss of locomotor function. Interestingly, two of four individuals with drug-abuse problems were bedridden with neuromuscular deterioration before the point of initiating renal replacement therapy. A majority of patients in each group suffered a loss of independence because dialysis infringed upon time commitments for other activities.

Table 2 helps to clarify major intragroup 2 differences. Subgroup D, "threatened to discontinue dialysis or never to start dialysis if not given a chance for a transplant," is characterized by relatively stable family and job situations. Subgroup E, "threatened to threaten to discontinue dialysis or never to start dialysis" is characterized by relatively unstable family and job situations. Personalities of patients in subgroup D were tougher, much more independent, at times gruff and grating, but with a soft core. Personalities of patients in subgroup E were in a state of disintegration because of real or imagined abandonment by usual support systems. Despite their apparent disarray, patients in subgroup E managed to thrash about sufficiently well until some greater response was forthcoming from the family or community. Sub-

group F contains the single patient who threatened to cause personal harm (without making any overt gestures). This young man was probably also threatening (indirectly to his family) to discontinue dialysis.

DISCUSSION

Psychological problems of diabetic patients with renal failure treated by dialysis were first analyzed by Compty et al.[1] Social and psychological rehabilitation of the diabetic transplant patient was initially studied by Simmons and Schilling.[2] From their observations certain valid background conclusions can be drawn.

Objective psychological testing has thus far been a poor guide for predicting the quality of adjustment to hemodialysis as well as the level of subsequent rehabilitation. Rehabilitation potential in diabetic patients with renal failure depends greatly on the degree of visual handicap, which has both physical and emotional components. A high incidence of marital discord occurs in diabetic patients with renal failure, partially explained by neuropathic impairment of sexual function in both men and women due to the addition of uremic neuropathy to long-standing diabetic neuropathy. It is not surprising that the early experience with home training of diabetic patients on dialysis included a nearly 50% incidence of emotional difficulties in the spouse.

Diabetic patients are likely to have many handicaps at the time they require dialysis. In addition to physical handicap, a systematic study by Simonds at the University of Missouri[3] has shown that poorly controlled diabetic patients (who presumably are more likely to suffer complications) have an increased frequency of anxiety and depression as well as both intrapersonal and nonintrapersonal conflicts when compared with a group of well-controlled diabetic patients. Since these handicapped patients have been living with an ongoing chronic disease, they begin life on dialysis at a somewhat lower level of self-esteem than nondiabetic patients with renal failure. As these patients experience greater expectations and aspirations for an improved life-style following transplantation, they become vulnerable to severe, and at times suicidal, depression if there is subsequent failure of the allograft. Whereas as many as 13% of diabetic renal transplantation patients were considered suicidal at some point in their clinical course, the renal team from Minnesota found that all but one of their reported patients had physically deteriorated before the point at which a psychiatrist found the emotional situation to be very precarious.

This study confirms those previous observations for diabetic patients on dialysis in terms of the patient's decision to either discontinue therapy, or to overtly attempt personal injury, or to repetitively noncomply with medical therapy to a total of about 6% of the patients at risk. We have added a further set of observations pertaining to a threatened refusal of therapy, amounting to another 4% of the patients at risk. This previously undescribed group is remarkable for powers of manipulative bargaining with real or imagined adversaries. The group that found the demands of life on dialysis (or following transplantation) disproportionately high, compared with the rewards, appears to start from a lower level of self-esteem, to have had more limited employment alternatives, to have survived with subliminal social support systems, and to have turned inward much aggression over the failure of doctors and nurses. The group that threatens to refuse dialysis if not given a chance for a transplant has had a more self-directed work history, has usually been married, is often engaged in personal struggles within the family, and is not ill-at-ease with strong positive or negative feelings concerning the health professionals close to them.

Profound visual impairment was the major handicap leading to loss of independence and self-esteem for the group that refused further therapy. Peripheral vascular disease with neuropathy diminished the walking of these patients about as much as for those patients who managed to survive despite threatening to quit the dialysis process. When eye surgery had failed to restore vision at about the time dialysis was initiated, there was a reactive depression much worse than that experienced when retinal hemorrhages occurred repeatedly within the first 6–12 mo of hemodialysis.

Kidney transplantation represented a last chance for some diabetic patients on dialysis. After the surgery, the patient manifested feelings of rebirth, anxiety, joy, and fear. Some had found dialysis tolerable only as long as there was anticipation of an allograft. If the transplant failed, however, the continuing emotional demands of chronic maintenance dialysis would be intolerable.

A given individual may take months to work through a personal and family solution to the change in life-style on dialysis. During that period of time, the health care team must be a resource for the patient, without making all the decisions for the individual. Each renal service would benefit from the sort of review presented here, since support mechanisms useful for one patient may be encouraged in another.

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